

# Misimagining the Unimaginable: The Disability Paradox and Health Care Decision Making

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Good decision making often requires accurate predictions about how potential outcomes will make one feel. However, people often mispredict the emotional impact of unfamiliar circumstances. For example, they often overestimate the emotional impact that chronic illnesses and disability will have on their lives. In the present article, the authors look at possible sources of error in both the happiness reports of patients with chronic illness or disability and the happiness predictions of healthy people asked to imagine the same illnesses and disabilities. On balance, the available evidence suggests that, whereas patients misreport their well-being, healthy people also mispredict the emotional impact that chronic illness and disability will have on their lives.

*Keywords:* quality of life, disability paradox, decision making, scale recalibration, adaptation

An important component of good decision making is being able to make accurate predictions about how one will feel if he or she experiences specific outcomes. This is true for everyday decisions as well as for rare, high stakes decisions in the medical domain. For example, a woman with a BRCA mutation who is at high risk for developing breast and ovarian cancer must decide whether to pursue prophylactic mastectomy and prophylactic oophorectomy to reduce her cancer risks. Such a decision hinges, in part, on what she imagines life would be like without her breasts or ovaries. If she imagines that removal of her breasts will bring her long-term unhappiness, she will be more likely to defer such a surgery. If she

imagines it will have little impact on her life, her decision will probably differ. In either case, if she misimagines the long-term sequelae of a prophylactic mastectomy, she could make the wrong decision.

Likewise, a man diagnosed with localized prostate cancer who is choosing between watchful waiting and a prostatectomy might try to envision what his life would be like with either approach. In imagining watchful waiting, he might consider the amount of worry he would experience day to day, knowing that a cancer still resides within his body. In imagining prostatectomy, he might consider how he would feel if he became impotent or incontinent as a result of the treatment. In either case, if he mispredicts the emotional consequence of these circumstances, he might choose the wrong treatment.

There is reason to be concerned that people mispredict the impact that circumstances will have on their well-being and quality of life (QoL). Across a wide range of health conditions, patients typically report greater happiness and QoL than do healthy people under similar circumstances (Ashby, O'Hanlon, & Buxton, 1994; Boyd, Sutherland, Heasman, Trichler, & Cummings, 1990; Buick & Petrie, 2002; Sackett & Torrance, 1978; Ubel, Loewenstein, & Jepson, 2003), a phenomenon that has been referred to as "the disability paradox" (Albrecht & Devlieger, 1999). The cause of such discrepancies could lie in faulty self-reports as well as in faulty imaginings (Ubel et al., 2003). In fact, some experts have raised plausible doubts about the self-reported happiness of people with chronic illness or disability (Schwartz & Sprangers, 1999; Wilson, 1999). If people are not as happy as they report being, then the disability paradox may arise simply because of these misreports. Perhaps healthy people are correct to imagine that they would be miserable if they experienced serious illness or disability.

In this article, we explore reasons for the disability paradox. In particular, we look at possible sources of error in both the happi-

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This work was funded by National Institutes of Health Grants RO1 HD40789-01, RO1 CA87595-01A1, and RO1 HD38963-02. We thank the many research assistants at the Program for Improving Health Care Decisions who helped with the studies we report here, Tammy Savercool for administrative assistance, and the many individuals who participated in these studies.

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ness reports of patients with chronic illness or disability and the happiness predictions of healthy people asked to imagine these same illnesses and disabilities (see Table 1 for a list of potential contributors to the disability paradox). On balance, the available evidence suggests that the disability paradox is not merely a result of patients misreporting (or exaggerating) their well-being; it also results because healthy people mispredict the emotional impact of chronic illness and disability.

### Potential Source of the Disability Paradox: Patient Misreports

#### Scale Recalibration

Imagine an 85-year-old woman who rates her health as 90 out of 100 and a 35-year-old woman who provides the same rating. How confident would you be that the two respondents mean the same thing by “90 out of 100?”

A concern among QoL and mood researchers is that the subjective scales used in such research are susceptible to *scale recalibration*. When people say that their health is “90 out of 100,” that their happiness is “7 out of 10,” or that their overall QoL is “very good,” these responses have little inherent meaning. What one person means by “90 out of 100” or “very good” could be different from what another person means. If these differential interpretations merely created noise in the data that researchers collect, then the ambiguity could be overcome by increasing sample size. But when people’s circumstances change, their interpretations of these kinds of subjective scales may change systematically in response. When people’s health declines, or when their age progresses, they might start reinterpreting what these response modes mean. Perhaps the disability paradox is to a large extent a result of scale recalibration.

We found evidence for scale recalibration among respondents to the Health and Retirement Study, a nationally representative sample of people 50 years and older in the United States (Ubel, Jankovic, Smith, & Fagerlin, in press). In a random subset of 1,031 members of this sample, we asked people to report their overall health on a 0 to 100 scale. Across subjects, we randomly varied the definition of “100” on the scale as either “perfect health,” “perfect

health for someone your age,” or “perfect health for a 20 year old.” Subjects’ responses supported the existence of scale recalibration. The mean health ratings of people informed that 100 represents “perfect health” and “perfect health for someone your age” were similar (73.1 and 72.9, respectively; *ns*), whereas ratings were significantly lower for those who were told that it represents “perfect health for a 20 year old” (with a mean of 65.0,  $p = .001$ , compared with both other groups).

These findings indicate that people spontaneously evaluate their health relative to a reference group of people their own age. Hence, not specifying an age comparison is equivalent to asking them to rate their health relative to others their own age. In the present study, this process resulted in an age-specific recalibration of the response scale, which implies that a 90 out of 100 from an 80-year-old can indeed mean something else than a 90 out of 100 from a 20-year-old.

Does such scale recalibration account for the disability paradox? Many QoL and happiness scales contain terms like *happiness*, *QoL*, and *life satisfaction* that can be reinterpreted by people when they face new circumstances. Nevertheless, in two studies, we have explored whether the disability paradox is attributable solely to scale recalibration and have found evidence to the contrary. For example, in an Internet study of 79 people, we assessed people’s QoL ratings for a series of common health conditions (Baron et al., 2003). Across ratings, we varied whether the response modes were ambiguous. We speculated that if scale recalibration accounted in significant part for discrepancies between patients and nonpatients, then such discrepancies would be reduced by the less ambiguous response modes. Instead, our results demonstrated that the discrepancy became even larger, a phenomenon we cannot currently explain.

In another study (Lacey, Fagerlin, Loewenstein, Smith, & Ubel, 2005), we asked 123 patients with emphysema (a chronic lung disease) to rate a series of health conditions (like diabetes and quadriplegia) and nonhealth conditions (like a nasty boss and a chronically difficult commute to work) on a 0 to 100 QoL scale. (This same scale is commonly used as a utility measure in cost-effectiveness studies; Gold, Siegel, Russell, & Weinstein, 1996.) When they completed this task, we then had them rate what their

Table 1  
*Overview of Potential Contributors to the Disability Paradox*

Potential contributors	Illustration
Patient misreports	
Scale recalibration	One person’s 90 out of 100 differs from another’s.
Conversational context	Patients respond differently when they know they are being surveyed as patients.
Theory-driven recall bias	I must have been less happy back then, because I think I am getting happier over time.
Global judgments vs. momentary moods	Despite experiencing moods of, for example, 5, 6, 5, 7, and 6 out of 10 over the past day, person reports experiencing an average mood of 7 out of 10.
Healthy people’s mispredictions	
Focusing illusion	When imagining colostomy, people focus narrowly on plastic pouches and bathing suits without considering life domains unaffected by a colostomy.
Underestimation of adaptation	People fail to consider how (and why) emotions are likely to change over time following the onset of an illness or disability.

QoL would be like if they had a chronic lung disease severe enough to make them short of breath after walking up one flight of stairs. For comparison purposes, we gave the same questionnaire to a convenience sample of 142 people without lung disease.

Our goal in this study was to see if the disability paradox could be explained by scale recalibration. If that were the case, then we would see systematically different use of the scale by emphysema patients compared with nonpatients. In other words, they not only would rate the lung disease scenario more highly than would healthy people (e.g., 75 for patients and 60 for the public) but would also rate diabetes and unemployment and a nasty boss more highly than would others. For example, each of these circumstances might be rated by patients 15 points higher than would be rated by the general public.

What did our actual data show? As predicted, the emphysema patients provided higher QoL ratings for the lung disease scenario than did healthy people. However, we found no evidence for scale recalibration. Both groups of subjects used the scale almost identically. Specifically, the average QoL scores given to the list of conditions was not higher for patients than for nonpatients. Also, the standard deviation of the scores did not differ across the two groups. Both groups used the scale the same way, while still differing in how they rated the lung disease scenario.

In summary, many subjective health scales are susceptible to scale recalibration, which could contribute to discrepancies between the QoL ratings of patients and the general public. But even in the absence of scale recalibration, such discrepancies can still occur. The disability paradox cannot be attributed solely to scale recalibration.

### *Conversational Context*

Before we discard scale recalibration as a major contributor to the disability paradox, however, it is useful to consider a possible complication. Suppose a man with Parkinson's disease receives a phone call and is told, "We are calling people with Parkinson's disease to find out about their quality of life and well-being." This introduction highlights Parkinson's patients as the relevant group of interest and clarifies that the interviewer is aware of the respondent's diagnosis. Under this condition, the respondent might calibrate the scale with other Parkinson's patients in mind, thus rating his health relative to a peer group of Parkinson's patients. In contrast, suppose that the interviewer says, "We are calling people in the Northeastern United States to find out about their quality of life and well-being." This introduction introduces the general population as the relevant group of interest, and the interviewer is presumably unaware of the respondent's diagnosis. In this case, the respondent may calibrate the scale with the general population in mind. As a result, the respondent's health rating should be more favorable when the survey is introduced as a study of Parkinson's patients than when it is introduced as a study of the general population. Because most health surveys honestly acknowledge their true purpose, this difference in conversational context could contribute to the unexpectedly favorable QoL reports provided by many patients.

We tested the influence of conversational context by interviewing a sample of 256 Parkinson's patients (Smith, Schwarz, Roberts, & Ubel, 2005), introducing the survey either as a survey of Parkinson's patients or as a survey of the general population. (At the conclusion of the interview, subjects were told the purpose of

the study and were given the opportunity to remove themselves from the study, which only 3 people chose to do.) Two results are noteworthy. First, as expected, Parkinson's patients reported higher health satisfaction when the survey was introduced as a survey of Parkinson's patients than when it was introduced as a survey of the general population ( $p < .05$ ). This further documents scale recalibration in the relevant domain. It also highlights that health surveys are likely to overestimate patients' health satisfaction by introducing other patients, rather than healthy people, as the relevant comparison group. Second, and in contrast to expectations, this recalibration did not generalize to ratings of general life satisfaction. Instead, respondents reported similar general life satisfaction under both conditions (*ns*). In fact, patients reported levels of life satisfaction similar to those reported in general populations.

What can be learned from this study? First, when patients report high levels of life satisfaction, this is not merely an artifact of conversational context. Regardless of whether we mentioned Parkinson's disease to these patients, they reported high levels of life satisfaction. However, this study provides a second important lesson. Conversational context can indeed influence patient self-reports. In this case, it increased their self-reported health (where, we should point out again, the meaning of "health" was ambiguous enough that people could recalibrate the scale). The effect of such conversational norms on self-reports should be further explored.

### *Theory-Driven Recall Bias*

The work of Michael Ross and his colleagues suggests another potential explanation for the disability paradox: People's reports of how their well-being has been changed by circumstances are often driven more by theory than by experience (for a review, see Ross, 1989). For example, Ross and his colleagues studied a group of college students who had enrolled in a study skills course that had no measurable effect on students' habits. Moreover, the students had good insight into their own study habits, with little difference between objective measures of their study habits and their self-reported study habits. Nevertheless, students incorrectly believed that the course had improved their study skills. They arrived at this conclusion by misremembering what their study habits were prior to the course—they recalled them as having been poorer than was the case. Ross has demonstrated this phenomenon in many other contexts, showing, for example, that people typically remember being less happy 5 years ago than they are currently, despite experiencing stable levels of happiness (Ross, 1989).

In a cross-sectional survey of 195 patients who had received colostomies at the University of Michigan over the past 10 years, we looked for evidence of theory-driven recall bias (Smith, Sheriff, Damschroder, & Ubel, 2005). We were able to do so because approximately half of the patients we surveyed had had their colostomies reversed. (For some people, it is possible to reconnect their bowels after they have experienced a colostomy for a while.) Across a wide range of QoL and mood measures, we found no significant differences between the patients who still had colostomies and those who had had their colostomies reversed. These two groups differ in many important ways, so we cannot conclude that colostomies have no effect on people's QoL. But the evidence suggests that the effects of colostomies on people's overall QoL are relatively minor.

Nevertheless, when we asked people to estimate how much colostomies affected their QoL, we found strikingly different attitudes across the two groups. For example, we asked people to imagine that they had 10 years (120 months) remaining in their lives and then asked them to tell us how much of that time they would give up to rid themselves of a colostomy. On average, those people who still had colostomies were willing to give up 12 of their remaining 120 months, whereas those who had had their colostomies reversed were willing to give up more than three times that amount. They responded in a way that suggests that their lives with colostomies were miserable. What could explain these very different opinions about colostomies?

We think people's theories about how colostomies had once influenced their lives overwhelmed their own experience with colostomies. They misremembered what it was like to experience a colostomy. This explanation is supported by other data. We asked these two groups to think back to how happy they had been earlier in their lives. The group that still had colostomies recalled high levels of prior happiness (higher than they were currently experiencing), whereas the group that no longer had colostomies recalled lower levels of happiness. People's memories appear, once again, to be influenced by their theories of how their happiness ought to be changed over time or across circumstances.

Whether such theory-driven recall bias contributes to the disability paradox depends on the methodology used. Most studies that have established a discrepancy have asked patients to report their current QoL, or to estimate the QoL of someone experiencing a condition similar to their own, and have asked healthy people to imagine what their QoL would be if they experienced the same illness or disability. In these studies, patients' self-reported QoL is not influenced by theory-driven recall bias because they are not being asked to recall anything. Other studies, however, ask patients how their QoL has been changed by their illness or disability. In fact, such global measures of change are becoming increasingly popular. Studies that use these measures are highly susceptible to the type of theory-driven bias discussed here.

### *Global Judgments Versus Momentary Mood*

Global reports of happiness and satisfaction with one's life as a whole are subject to pronounced context effects and raise numerous methodological concerns (for a review, see Schwarz & Strack, 1991). In response to these concerns, several researchers have suggested that moment-to-moment measures of mood may be a better indicator of people's subjective QoL (for a discussion, see Kahneman, 1999). Would such moment-to-moment measures of affect differ enough from patients' global reports to account for the disability paradox?

To explore this issue, we conducted a study comparing global mood estimates to moment-to-moment moods in a sample of 49 dialysis patients and 49 healthy controls (matched by age, race, gender, and education) (Riis et al., in press). First, we asked subjects to tell us on a scale ranging from  $-2$  (*very unpleasant*) to  $2$  (*very pleasant*) what their distribution of moods was in a typical week. Across the two groups, we found almost no difference in these global mood estimates, with both groups stating that they experienced positive moods the majority of the time. However, earlier research has shown that such retrospective reports are not very reliable (Kahneman, 1999). Hence, we complemented these retrospective measures with concurrent measures of mood by

using experience sampling methodology (Schimmack, 2003). Specifically, we gave each subject a Palm Pilot that was programmed to beep at random intervals throughout the week to ask them about their current mood on this same scale (as well as on a 0–4 scale for a series of positive and negative moods).

There are several reasons to believe that moment-to-moment measures are more accurate than global measures. For example, when making global assessments, people place disproportionate weight on their recent moods (Kahneman, Fredrickson, Schreiber, & Redelmeier, 1993). Likewise, global appraisals are influenced by current moods. Global reports of well-being, for example, are significantly increased when researchers arrange for people to experience a mildly positive event, like finding a dime on a photocopier machine (Schwarz & Strack, 1991). With data collection across an entire week, the influence of such ups and downs should average out.

What did we find when we looked at the moment-to-moment moods of these two groups of people? Their moods were indistinguishable ( $p > .1$ , for all comparisons). Both groups reported experiencing positive moods significantly more often than negative moods. And the overall balance of positive and negative moods experienced over the course of the week was very similar to the global estimates each group had given prior to recording their experience over the ensuing week.

Although these two groups of people reported strikingly similar moods over the course of one week, neither group predicted such similarity. For example, when imagining they had kidney failure, healthy people predicted being in unhappy moods (less than 0 on the  $-2$  to  $2$  scale), a prediction sharply at odds ( $p < .01$ ) with patients' moment-to-moment mood reports. This misprediction fits the pattern we are investigating in many of our studies, with healthy people underestimating the well-being of people with chronic illness or disability. In addition, when imagining they had never experienced kidney failure, dialysis patients predicted experiencing extremely high levels of positive affect, significantly higher than the moment-to-moment moods reported by healthy people ( $p < .01$ ). Again, it appears that people's theories cause them to miscalculate the moods of people whose circumstances differ from their own.

### Summary So Far

The preponderance of evidence suggests that many patients with chronic illness and disability are able to emotionally adapt to their circumstances and experience relatively high levels of mood and QoL. Such adaptation is not always complete. Indeed, when people experience multiple disabilities, their well-being declines significantly (Mehnert, Krauss, Nadler, & Boyd, 1990). Nevertheless, the phenomenon we are studying is the discrepancy between the well-being reported by people with illness or disability and the predictions of healthy people. Even when patients do not fully adapt to their illnesses, they frequently report higher levels of well-being than what is imagined by healthy people under similar circumstances.

Much more work needs to be done to explore potential sources of bias in the QoL and mood reports of people with chronic illness and disability. Nevertheless, so far it appears that the disability paradox cannot be blamed solely, or even primarily, on patient misreports. Although some kinds of self-reports are susceptible to scale recalibration, such recalibration does not fully account for the

gap between patients' self-reported well-being and healthy people's imaginings. Thus, in looking for sources of the disability paradox, it is necessary to explore why healthy people might mispredict what their QoL would be if they experienced chronic illness or disability.

### Another Potential Source of the Disability Paradox: Healthy Mispredictions

#### *Mispredictions Resulting From a Focusing Illusion*

Imagine, for a moment, that you have a colostomy as a result of colon cancer. What would your life be like? When most people imagine the situation, images of plastic pouches come to mind. They think about being unable to go outside in a bathing suit because of their colostomy. And whereas all those imaginings might be accurate, there is a whole world of imaginings that people typically leave out. They do not consider the hundreds of routine daily activities that will be unaffected by their colostomy—things like watching TV shows, enjoying good conversations, savoring tasty meals, and the like. They may even overlook the fact that they haven't worn a bathing suit in public in years.

Schkade and Kahneman describe this phenomenon as a *focusing illusion* (Schkade & Kahneman, 1998). When imagining unfamiliar circumstances, people focus narrowly on the most obvious difference between those circumstances and their current circumstances and thereby mispredict the emotional impact of the change in circumstances. For example, college students living in the midwestern United States report similar levels of happiness as do those living in southern California. And yet, students in both locations predict that life would be better in California than in the Midwest. Focused narrowly on the better climate in southern California, students downplay all the non-weather-related things that make college life enjoyable or unenjoyable. They seem to forget that happiness in college depends more on the kind of friends you hang out with than on whether you can hang out with them in consistently sunny weather.

Focusing illusions might contribute to the disability paradox by causing the general public to overestimate the emotional impact of chronic illness or disability. If people focus very narrowly on those domains of their lives that are influenced by illness and disability, they will imagine being much less happy than they really would be.

As we were interested in trying to improve the way people imagine life with illness or disability, we tried several ways of reducing the impact of focusing illusions on people's predictions of what it would be like to experience chronic illness or disability. Across a series of experiments, we asked people to rate the QoL they think they would experience if they were to develop paraplegia or below-the-knee amputation (with a functioning prosthesis). We tried to *defocus* people by getting them to think more broadly about how such disabilities would influence their lives. For example, we asked some people to think about how the disability would affect a broad array of life domains such as family life, social life, or spiritual life (Ubel et al., 2001). We asked others to imagine how disability would influence their experience of concrete events like visiting with friends or family, paying bills and taxes, and reading books or watching TV (Ubel, Loewenstein, & Jepson, in press). We asked others to think very specifically about the activities that had consumed the largest portion of their time over the preceding 24 hr and to predict how the experience of these activ-

ities (typically things like "working at my desk" or "watching TV") would be affected by the disability in question. In addition, we asked another group to list aspects of their life that would be harmed, improved, and unaffected by the disability (Ubel, Loewenstein, & Jepson, in press).

Across these defocusing tasks, we expected that people's global estimates of QoL with disability would be increased. That is, after they thought more broadly about how disability would influence their lives, they would acknowledge that its effects were smaller than they had anticipated.

As predicted, we found that many people increased their estimates of the QoL they would experience if they had these disabilities. But these people were in the minority. More often, across more than a dozen studies and more than 1,000 participants, people's predictions of what it would be like to experience these disabilities were either unchanged by the defocusing task or went in the opposite direction we expected, with people thinking these disabilities would make them even more miserable than they had originally predicted. These findings indicate that it is difficult to overcome people's focusing illusions.

#### *Mispredictions Resulting From Underestimation of Adaptation*

Many people with chronic illness and disability adapt to their circumstances. If healthy people do not take this adaptation process into account, or underestimate its power, they are bound to arrive at overly pessimistic predictions about illness and disability, further contributing to the disability paradox.

One way in which people adapt is to find ways to physically deal with their new circumstances. A patient with rheumatoid arthritis finds new kitchen utensils to make it easier for him to work around the house and purchases clothing that is easier to get on and off with painfully swollen hands. In addition, people adapt psychologically by shifting their goals and priorities in life. They reduce their expectations for what they can accomplish in domains of their life that have been influenced by illness or disability (Lepore & Eton, 2000). They find meaning and purpose in other aspects of their lives. They may even redefine, to themselves, what it means to be happy.

Are healthy people's predictions influenced by failure to consider adaptation? As with our focusing illusion studies, we asked people to imagine what their life would be like if they experienced a chronic disability such as paraplegia (Ubel, Loewenstein, & Jepson, in press). Then we asked them to think back on experiences that they had had more than 6 months ago that had brought them either a great deal of sadness or a great deal of happiness and to reflect on whether their emotions became stronger or weaker over time.

In response to this adaptation exercise, people significantly increased their predictions of the QoL they would experience if they developed paraplegia (Ubel, Loewenstein, & Jepson, in press). In an Internet study, we replicated this result with a person tradeoff utility elicitation task (Damschroder, Zikmund-Fisher, & Ubel, in press). Simply reminding people about adaptation made them more inclined to accept the idea that people with chronic disabilities can still find some amount of happiness. However, such increases were only modest, raising questions about whether people underestimate their ability to adapt to bad circumstances.

### Final Thoughts

People experiencing a wide range of illnesses and disabilities often report paradoxically high levels of QoL and mood. Many people are understandably skeptical that such self-reports are accurate. However, to date, across a wide range of studies, the best available evidence suggests that such self-reports are largely accurate. Even when care is taken to explore for scale recalibration, and even when great effort is taken to collect data on moment-to-moment mood rather than relying on global self-reports, the disability paradox persists: People experiencing chronic illness and disability are happier than what healthy people predict they would be under similar circumstances.

In sum, people's tendency to focus on core changes and to ignore or underestimate the beneficial effects of adaptation contributes to hedonic predictions that are more extreme than warranted. These extreme predictions contribute to the phenomenon of the disability paradox. Moreover, they put people at risk for making poor decisions such as moving to California only to find out that the pleasures of good weather fade or avoiding a colostomy that seems unbearable.

The relevance of this research for cancer decision making requires further study. Nevertheless, hedonic predictions likely play a large role in many patients' decisions. Earlier, we described how such mispredictions could influence decision making about prostate and breast cancer. It could also influence treatment decisions. For example, many patients with metastatic cancer face a choice between palliative care and chemotherapy. If such patients overestimate or underestimate the well-being they would experience while undergoing chemotherapy, they could make wrong decisions.

Early evidence suggests that it is very difficult to help people to do a better job of imagining how chronic illness and disability will affect their lives. People often overestimate the emotional impact of chronic illness and disability, through focusing illusions and through a failure to consider adaptation. Focusing illusions are extremely difficult to eradicate. And although people are open to the idea that they will adapt to their circumstances, it is doubtful that they fully appreciate how much they are likely to adapt. These misestimates could cause people to make inappropriate decisions in their lives. It is necessary to develop and test different ways to get people to imagine unfamiliar health states and to recognize the power of emotional adaptation.

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